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## Original Research

## The health, well-being and future opportunities of young carers: a population approach

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## ABSTRACT

**Objectives:** There is a lack of evidence on the health-related impacts of being a young carer. This article takes a population approach to young carer research specifically to investigate the prevalence of young carers and explore differences in their health, well-being and future expectations.

**Study design:** This is a cross-sectional regression analysis.

**Methods:** Secondary analysis of a representative Scottish secondary school survey was undertaken. Pupils with caring responsibilities were identified, and their outcomes in terms of physical and mental health and postschool expectations were analysed.

**Results:** Almost one in eight (12%) surveyed reported caring for someone in the household. Young carers' physical and mental health and psychosocial outcomes were significantly poorer, and they were significantly less likely to see themselves entering further or higher education.

**Conclusion:** This research suggests that Glasgow could have many more young carers than previously thought and provides clear evidence that young people's outcomes are influenced by carer status.

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## Introduction

Young carers are those younger than 18 years providing care, assistance or support to another family member.<sup>1</sup> It is difficult to estimate how many young carers currently live in Scotland: the 2011 Scottish census identified that 1.4% of those younger than 16 years had caring responsibilities, while the Scottish Health Survey in 2012–2013 identified 4% of those aged 4–15 years as carers.<sup>2</sup>

Adults who provide unpaid care are more likely than their non-caring counterparts to have poorer health outcomes, in terms of both self-reported<sup>3</sup> and objective measures.<sup>4</sup> These differences may be caused by a number of factors: strain through physical exertion; changes in health due to health behaviours such as diet and exercise; and physiological effects of psychological distress.<sup>5</sup>

Young carers have similarly reported several physical health issues stemming directly from their caring responsibilities, including tiredness, exhaustion and backache, and project workers who work with them have reported that they have seen evidence of

the impact of caring on both the diet and exercise of young carers.<sup>6,7</sup>

Young carers are also more likely to report negative mental health and well-being; 4% of young adult carers in Scotland have a mental health condition, compared with 1% of non-carers.<sup>2</sup> In a United Kingdom (UK) study, Becker and Becker<sup>6</sup> found that young carers reported worry, stress, anxiety, depression, anger, upset, resentment and resignation. Others have found that in comparison with their non-caring counterparts, young carers were significantly more depressed and had lower self-esteem<sup>8</sup> and reported being less happy.<sup>9</sup>

The relationship between being a young carer and the impact on mental health and well-being is not straightforward. The type of illness or disability, the frequency and duration of care and the type of tasks undertaken can all have a differing effect, as can the socio-economic situation of the family and the type and frequency of social support received.<sup>10</sup> Moreover, some young carers have also reported positive outcomes from caring, such as closeness to family, a sense of responsibility and a source of practical life skills.<sup>11</sup>

Caring may further impact a young person's participation and success in education, which is a key social determinant of health.<sup>12</sup> A longitudinal study of young carers found that 1 in 20 had missed

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school owing to caring responsibilities; they had significantly lower achievement at General Certificate of Secondary Education and were more likely to end up outside the education system and out of work or training.<sup>13</sup> Butler and Astbury<sup>14</sup> found that young carers who provided emotional support for others had negative experiences with schooling, such as poor attendance and bullying, as well as stigma and feelings of isolation. In a separate study, when compared with non-carers, young carers were also more likely to report that they 'sometimes' or 'often' were afraid to go to school owing to bullying.<sup>8</sup> Some young carers have also been found to display 'limited horizons', wherein thinking about the future is restricted by caring responsibilities.<sup>15</sup> These experiences may in turn make the transition from school to either higher education or the labour market more challenging for young carers.

The current research draws from a population survey of school pupils in Glasgow, Scotland, and summarises the results of analyses on the health, well-being and future expectations of young carers.

The central aims of the article are to (1) investigate the prevalence of young carers and (2) explore any differences between young carers and their non-carer counterparts, in terms of physical, emotional and mental health and postschool expectations.

## Methods

### Participants

Data were collected through the 2014–2015 survey of Glasgow city schools, which was completed by 11,215 secondary school pupils, aged 11 to 18 years. All secondary schools in the city were contacted and provided with an information pack that detailed the aims of the project. Parents were contacted to inform them that the survey was taking place and to provide an opportunity to opt out from participating. Pupils were provided with an information sheet that outlined the aims of the survey, explained their anonymity and explained how the results would be used.<sup>16</sup>

Young carers were identified through a two-step process: (1) the pupil self-reported that someone in their family household had a disability, long-term illness, drug/alcohol problem or mental health problem, and (2) the pupil reported that they looked after or cared for this person.

### Measures

Four outcome measures were examined: physical health conditions, mental health conditions, psychosocial difficulties and postschool expectations. (The full methodology can be found in the original report.<sup>17</sup>)

Physical health conditions were measured by whether the pupil reported having one or more of a list of conditions listed in the survey: asthma; diabetes; eczema/psoriasis; epilepsy; arthritis/painful joints; cystic fibrosis; stomach/digestion, constipation or bowel problem; urinary/bladder problems (wetting); hearing impairment; visual impairment or other physical illness or disability.

Mental health conditions were measured using a single item by asking pupils whether they had a mental health/emotional illness.

Psychosocial difficulties were measured using the Total Difficulties scale from the Strengths and Difficulties scale.<sup>18</sup> These scores were analysed as a continuous variable to maximise the available statistical power.<sup>19</sup>

Postschool expectations were measured by asking pupils to select from a list of options on what they thought that they would do after they left school. The options were as follows: working; trade or modern apprenticeship; university; further education college; take a gap year; volunteering; setting up a business;

training programme; don't know; and other. The responses were collapsed to form a dichotomous variable reflecting 'further or higher education' or 'something else'.

### Analytical approach

Regression analyses were used to assess the relationship between carer status and each of the four outcomes. Two models were run for each outcome. In the first model, the outcome variable was regressed on carer status only. In the second model, various sociodemographic variables were included to control for sex, age, deprivation, ethnicity and whether the pupil lived in a lone-parent family. Indicators of illness in the family were also included, to try and isolate the effects of providing care over and above living with a family member with a disability, long-term illness, drug/alcohol problem or mental health problem.

Linear regression was used for mental health measurements as they were continuous numeric variables, and logistic regression was used for binary outcomes, such as postschool expectations, emotional difficulties and physical health conditions. Therefore, the coefficients for postschool expectations, emotional difficulties and physical health conditions are presented as odds ratios (ORs), and those for mental health are presented as standardised beta coefficients ( $\beta$ ).

## Results

Overall, 12% (1341 pupils) of the sample was identified as being a young carer through this process.

More than half of these young carers (54.5%) cared for someone with a disability; more than one-third (34.8%) cared for someone with a long-term condition; almost a quarter (23.9%) cared for someone with a mental health problem; and just more than one-tenth (10.7%) cared for someone with a drug or alcohol problem.<sup>a</sup> Further demographic variables of the sample are presented in Table 1.

Overall, 33% of pupils reported having at least one limiting illness or disability, while 5% responded affirmatively to having a mental health/emotional illness. In total, 64% of pupils said they expected to go on to further or higher education.

Descriptive statistics are presented in Table 2. The results of the regression analyses are presented in Table 3.

The first models in Table 3 show that caring status was associated with each of the four outcome variables. Young carers were more likely to report both physical (OR = 1.75,  $p < 0.01$ ) and mental health problems (OR = 2.80,  $p < 0.01$ ), were less likely to think that they would attend further or higher education (OR = 1.33,  $p < 0.01$ ) and reported higher levels of psychosocial problems ( $\beta = 0.14$ ,  $p < 0.01$ ). Including covariates in these models attenuated the relationship between carer status and physical health problems (OR = 1.15,  $p > 0.05$ ), although the relationships between carer status and the remaining three outcome variables remained significant ( $p < 0.01$ ).

## Discussion

One in eight (12%) of the school pupils surveyed reported providing care, which is considerably higher than previous national estimates<sup>2</sup> and may be attributable to the relatively high levels of deprivation and poor health in Glasgow.<sup>20</sup> This represents a sizable proportion of the school-aged population, although only 300 young

<sup>a</sup> Please note these figures do not add up to 100% as more than one option could be chosen here.

**Table 1**  
Descriptive variables for carers and non-carers.

Descriptive variables	Non-carer (%)	Carer (%)
Gender		
Female	50.9	57.6
Male	49.1	42.4
Deprivation (free school meals registered)	20.7	33.0
Ethnicity		
White, UK	85.4	85.2
Non White, UK	14.6	14.8
Lone-parent family	29.8	34.5
Age (years)		
11	3.9	3.2
12	17.4	15.6
13	17.9	17.2
14	19.4	19.9
15	17.5	18.4
16	14.4	14.6
17	9.3	10.8
18	0.2	0.3

UK = United Kingdom.

**Table 2**  
Outcome variables for carers and non-carers.

Outcome variables	Non-carer	Carer
Total Difficulties score (mean)	11.7	14
Postschool expectations: further or higher education	64.9%	58.1%
Mental health conditions	4.0%	10.6%
Physical health conditions	31.2%	44.3%

carers received support from social services in the financial year 2015–2016,<sup>21</sup> which implies that many living in the city are unknown to services. There are several reasons why young carers may be reluctant to be identified as such and therefore remain hidden to services. Some may not perceive themselves as carers, instead view their caring responsibilities as a ‘normal’ aspect of helping family members. Forms of stigma associated with particular health conditions may also cause young carers to fear rejection or discrimination from their peers, while others may seek to conceal their family situation from services owing to a fear of unwanted intervention and forced separation.<sup>22,23</sup>

Young carers also reported poorer physical, mental and psychosocial outcomes than young people who do not provide care. These findings support previous research demonstrating that young carers are more likely to report physical health problems and poorer self-rated overall health than their peers.<sup>2,24</sup> These self-report data are further supported by research demonstrating that young carers have an increased mortality risk.<sup>25</sup> On the other hand, Tseliou et al.<sup>25</sup> report that young carers are less likely to report chronic mobility problems overall and that only young carers younger than 18 years who provide a relatively intense level of care are at a higher risk of such conditions. Young carers do not always report poorer physical health therefore, and the effect may be modified by factors such as age and the level of care provided. The present findings also support previous research showing that young carers are more likely to report mental health problems than their peers,<sup>2,25</sup> including higher levels of depressive symptoms and lower levels of self-esteem and happiness.<sup>9,26</sup> On the other hand, providing care may also be associated with certain positive psychosocial outcomes for young people.<sup>27</sup> Future research should seek to identify and understand these potential assets, which could be drawn upon to better support this population.

**Table 3**  
Multivariable regression models testing the associations between explanatory and outcome variables.

Covariates	Physical health condition		Mental health condition		Psychosocial difficulties		Postschool expectations (something other than further education)	
	Exp(B)	95% CI	Exp(B)	95% CI	β (standardised B)	95% CI	Exp(B)	95% CI
Model 1								
Carer	1.75**	1.55, 1.98	2.80**	2.27, 3.46	0.14**	0.09, 0.19	1.33**	1.16, 1.53
Model 2								
Carer	1.15	0.97, 1.36	1.35**	1.11, 1.64	0.04**	0.02, 0.05	1.33**	1.1, 1.62
Male	0.84**	0.77, 0.92	0.98	0.86, 1.11	−0.13**	−0.10, −0.16	2.19**	1.98, 2.42
Age	1.03*	1.00, 1.06	1.04*	1.00, 1.08	0.10**	0.09, 0.10	0.86**	0.84, 0.89
Free school meal	1.10	0.99, 1.24	1.01	0.87, 1.17	0.03**	0.02, 0.04	1.31**	1.16, 1.49
Non-white ethnicity	0.85*	0.74, 0.97	0.52**	0.42, 0.64	−0.03**	−0.02, −0.05	0.35**	0.30, 0.42
Living in a lone-parent family	1.12*	1.01, 1.24	1.12	0.98, 1.28	0.05**	0.04, 0.07	1.17**	1.05, 1.30
Disability in the household	1.33**	1.14, 1.56	1.60**	1.33, 1.93	0.05**	0.03, 0.08	1.18	0.98, 1.41
Long-term illness in the household	1.39**	1.18, 1.65	1.27*	1.03, 1.56	0.06**	0.03, 0.09	0.84	0.69, 1.03
Drug or alcohol problem in the household	1.56**	1.23, 1.97	2.18**	1.68, 2.83	0.09**	0.03, 0.15	1.15	0.88, 1.51
Mental health problem in the household	1.79**	1.50, 2.14	3.02**	2.50, 3.66	0.12**	0.06, 0.17	1.00	0.81, 1.23

CI = confidence interval.

\*p &lt; 0.05.

\*\*p &lt; 0.01.

The findings of this study reinforce the need for a range of services and interventions being made available to support these children and young people. General practice has an important role to play as it is likely to be the first point of contact that young carers' families have with universal healthcare services. General practitioners (GPs) are generally aware of the issues that carers face and believe that they have a role in supporting them, although they report a lack of confidence and training in identifying and supporting those who provide unpaid care.<sup>28</sup> Routine enquiry approaches may be helpful in identifying young carers, although additional resources and new forms of partnership working between adult and children's services will be required to provide an appropriate and sustainable response. In Scotland, the introduction of GP Link Workers provides an opportunity to increase the level of tailored support and social prescribing offered to young carers.<sup>29</sup>

Young carers were also less likely to see themselves as going on to further or higher education. Notably, the presence of an illness in the family was not associated with future expectations, which suggests that there is something about the role and responsibilities of being a young carer that shapes adolescents' views of the future. This finding is consistent with the concept of 'bounded agency' that describes how young carers' choices are constrained by their caring responsibilities. An Australian qualitative study of young carers found that caring responsibilities did not appear to affect their aspirations to attend university but did affect their choices of university to attend, their choices of the course to study and the hours that they could attend.<sup>30</sup>

The beliefs captured in the present study may also be an important precursor to young carers' eventual disadvantage in the labour market. Data from the Longitudinal Survey of Young People in England, for example, showed that young carers in work at the ages of 20 and 21 years were more likely to be in lower skilled occupations than non-caring counterparts.<sup>13</sup> As such, these findings demonstrate how caring not only can impact the immediate health and well-being of young people but also may shape the later social determinants of adult health, such as education and employment trajectories.

In addition to greater caring responsibilities and activities, socio-economic differences between young carers and their peers may also be important factors that underpin the results reported here. For example, children living in a lone-parent household are more likely to be a carer (6.6%) than those from a two-parent family (2.5%),<sup>2</sup> and one Scottish survey suggests that young carers are more likely to live in areas of multiple deprivation.<sup>31</sup> Moreover, households with young carers have become disproportionately vulnerable to child poverty in recent years—compared with other households with children—suggesting that young carers have been particularly adversely impacted by the financial crisis and ensuing period of austerity and welfare reform.<sup>32</sup> As child poverty is currently projected to increase over the coming years in Scotland, it will be important to monitor how young carers are affected in particular and to account for this in service planning and delivery.

### Limitations

The measures used did not assess the types of care provided by the respondents, which may be important effect modifiers of the association between carer status and health outcomes.<sup>33</sup> Moreover, it is unclear to what extent a self-complete questionnaire would lead to an overidentification of young carers.

### Conclusion

The UK has been shown to have an advanced awareness of and response to the needs of young carers in terms of research and

specific policy;<sup>34</sup> however, as this study has shown, the outcomes for these young people are poorer than for non-carers. Although young carers' services exist and serve an extremely valuable role in providing respite and support, a whole-system approach must be operationalised from health, social care and educational services to ensure that young carers are able to maximize their capabilities and have control over their lives.<sup>1</sup>

### Author statements

#### Ethical approval

NHS ethical approval was not required for the survey, which was conducted by NHS Greater Glasgow and Clyde on behalf of Glasgow City Council Education Department, after approval from the Director of Education.

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#### Competing interests

None declared.

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